



May 18, 2021

Health Policy Committee
Anderson House Office Building
124 North Capitol Avenue
Lansing, MI 48933

Re: HB 4762

Dear Chair Kahle, Vice-Chair Witwer and Members of the Health Policy Committee:

As the leading human rights organization for all individuals with Down syndrome, the National Down Syndrome Society (NDSS) strongly supports the passage HB 4762, which prohibits discrimination against organ transplant recipients based on physical or mental disability.

NDSS is the largest nonprofit representing and advocating for people with Down syndrome and their families. With over 300 affiliate groups spanning across the country, NDSS has worked tirelessly on the federal, state and local levels to break down barriers and create opportunities for individuals with Down syndrome to be included in all aspects of society and fulfill their hopes and dreams. Advancing science and medicine has changed the life expectancy of an individual with Down syndrome from 25 years old in 1983 to 60 years old today. Individuals with Down syndrome are living longer, healthier lives, attending postsecondary education programs, obtaining employment, getting married, living independently and are productive members of their local communities.

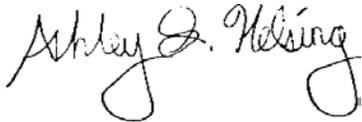
This bill will seek to affirm that the Michigan Legislature is committed to eliminating discrimination by ensuring that individuals with disabilities are not denied access to organ transplants based solely on their disability. A study by Stanford University showed that 85 percent of pediatric transplant centers consider intellectual or developmental disabilities when determining eligibility for transplants. Additionally, 71 percent of heart programs also consider disabilities as a factor.¹

There are currently laws against organ transplant discrimination in the states of Arkansas, California, Delaware, Florida, Indiana, Iowa, Kansas, Louisiana, Maryland, Massachusetts, Missouri, New Jersey, Ohio, Oklahoma, Oregon, Pennsylvania, Virginia, Washington and Wyoming. An important piece of the legislation in the above states is enforcement. While NDSS supports HB 4762 in Michigan, we hope you will include a section on enforcement to bolster

the antidiscrimination section.

We hope that Michigan will pass this legislation with an added section on enforcement to eliminate discrimination for organ transplants on the basis of disability. This bill will save lives. Thank you for your leadership with regard to this important piece of legislation.

Sincerely,

A handwritten signature in black ink that reads "Ashley S. Helsing". The signature is written in a cursive style with a large, looped 'S' and 'H'.

Ashley Helsing

Director of Government Relations

National Down Syndrome Society

AHelsing@ndss.org

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¹Richards CT, Crawley La Vera M, Magnus D. Use of neurodevelopmental delay in pediatric solid organ transplant listing decisions: Inconsistencies in standards across major pediatric transplant centers. *Pediatric Transplantation* 2009;13:843–850